

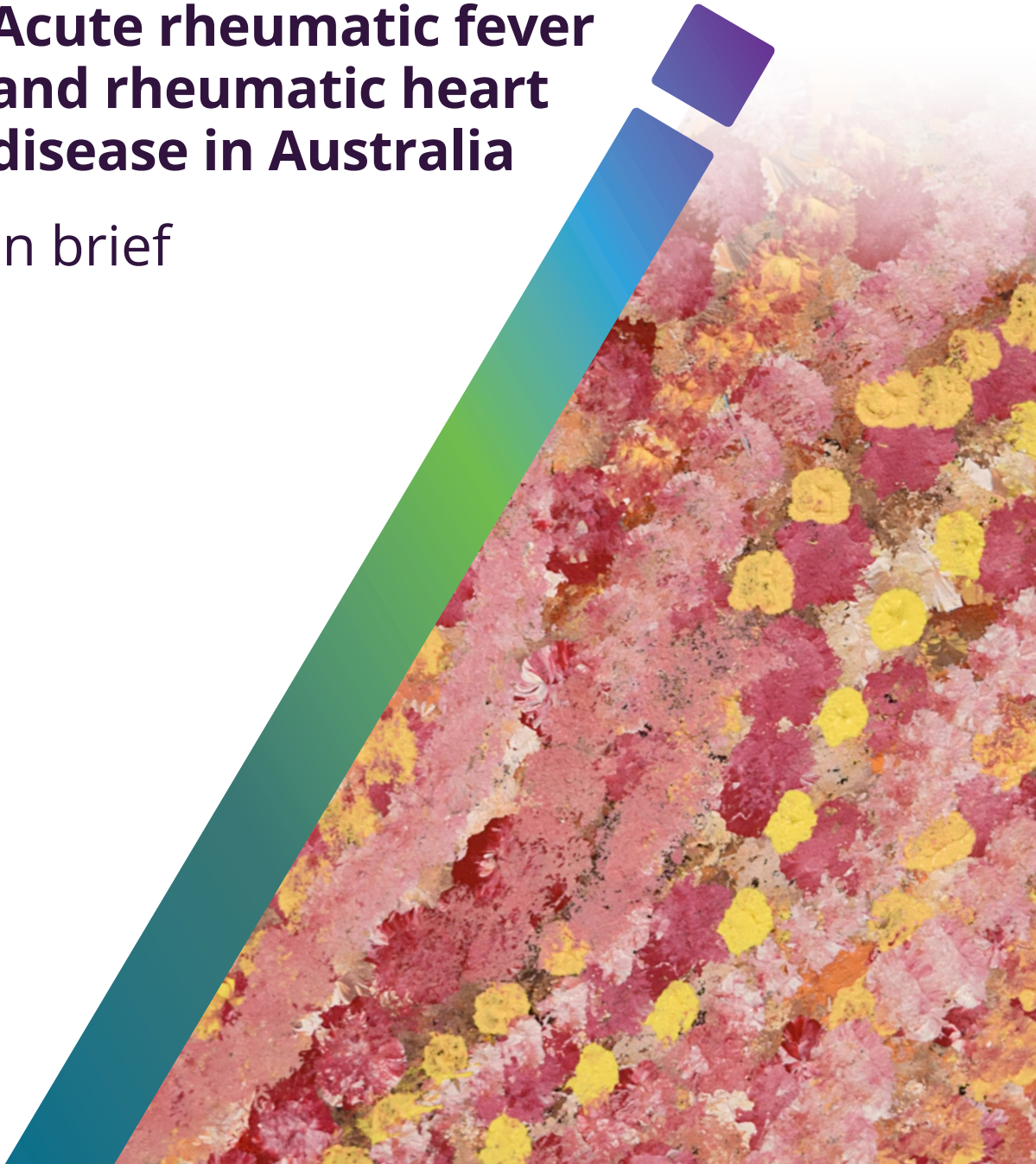


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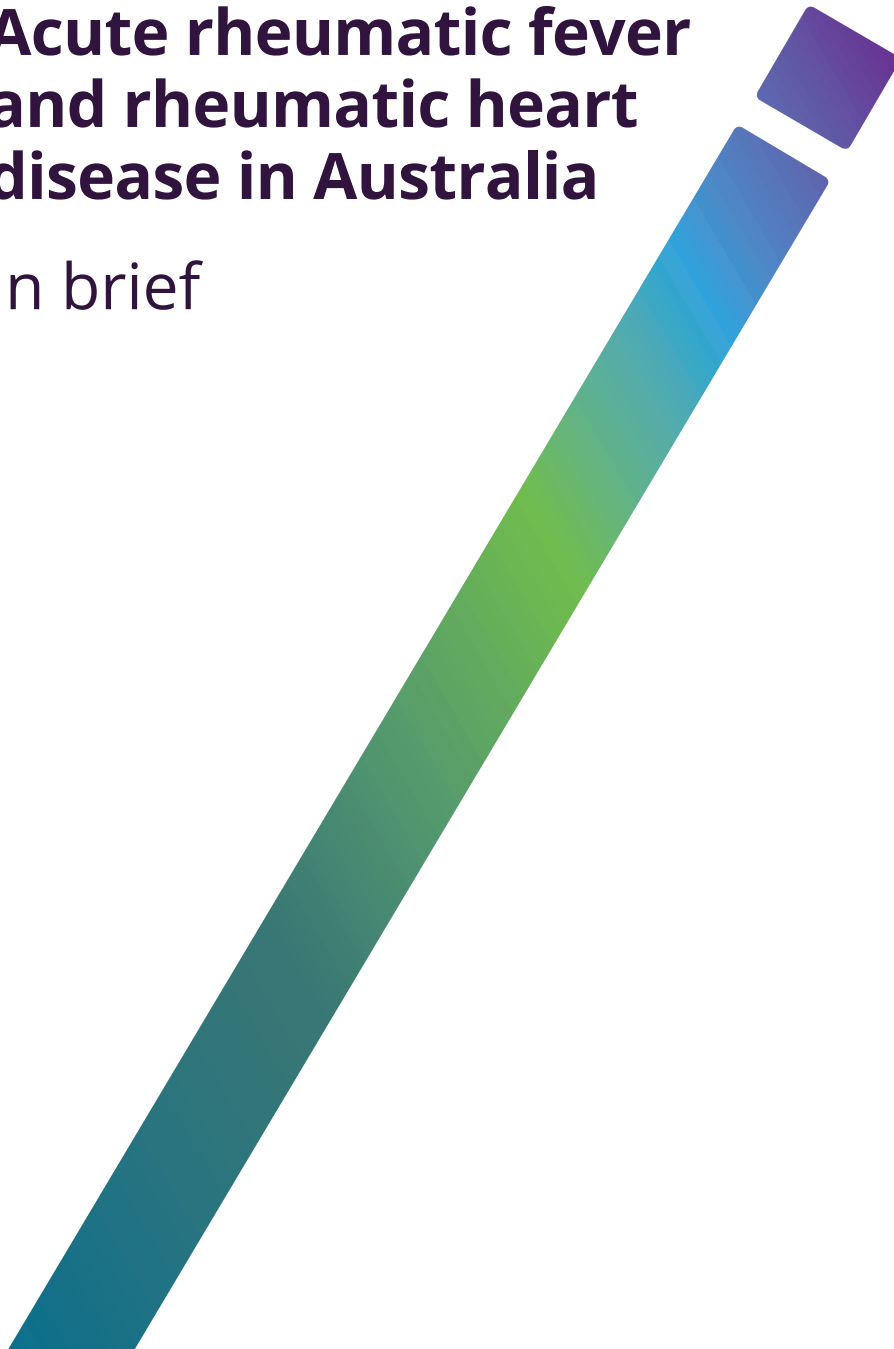
Acute rheumatic fever and rheumatic heart disease in Australia

In brief




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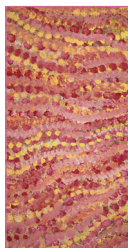
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1 Introduction

Under the Rheumatic Fever Strategy, the Australian Government provides funding to support rheumatic heart disease (RHD) control programs in Queensland, Western Australia, South Australia and the Northern Territory. This section provides an introduction on acute rheumatic fever (ARF) and RHD in Australia.

This in-brief report provides an overview of the data in the main report, also titled 'Acute rheumatic fever and rheumatic heart disease in Australia'.

What is acute rheumatic fever?

ARF refers to an autoimmune response to infection of the upper respiratory tract (and possibly of the skin) by group A streptococcus bacteria. ARF can affect the heart, joints, brain, and subcutaneous tissues (the innermost layers of skin) (Parnaby & Carapetis 2010). While there is no lasting damage caused to the brain, joints, or skin, ARF can cause lasting damage to the heart.

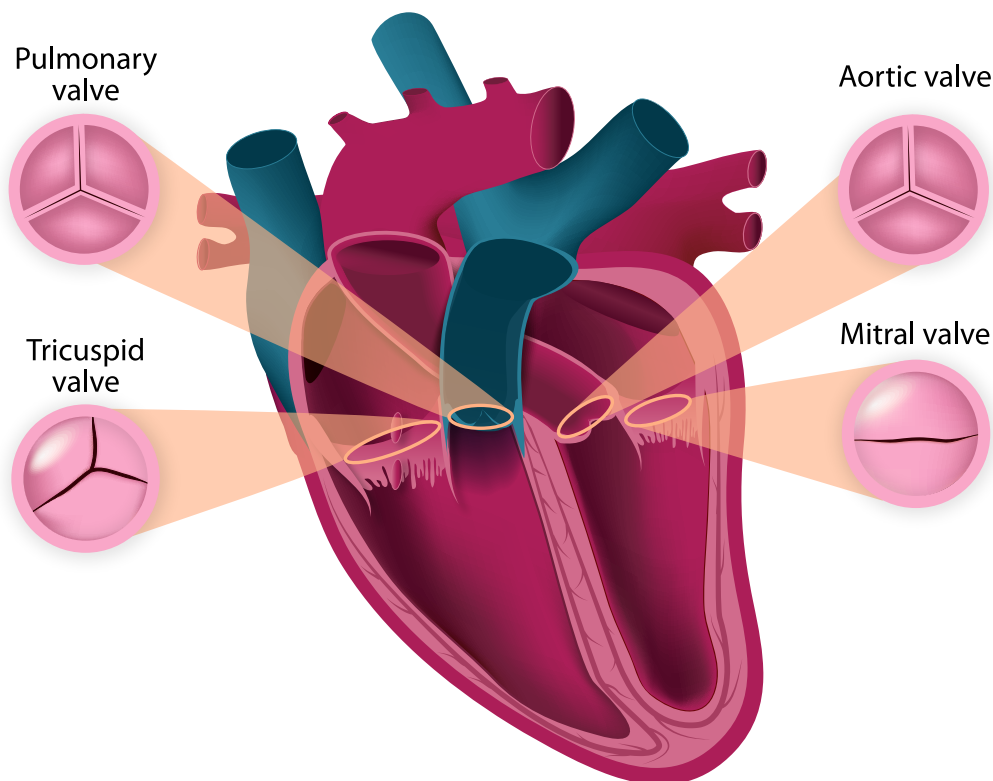
What is rheumatic heart disease?

RHD is caused by damage to heart valves as a result of a single or many ARF episodes. An affected heart valve might:

- become scarred and stiff, obstructing blood flow (called 'stenosis')
- fail to close properly, causing blood to flow backwards in the heart instead of forward around the body (called 'regurgitation'); regurgitation due to damage to the mitral valve is the most common feature of RHD (RHD Australia et al. 2012).

Figure 1.1 shows a diagram of the heart, with the heart valves that might be affected.

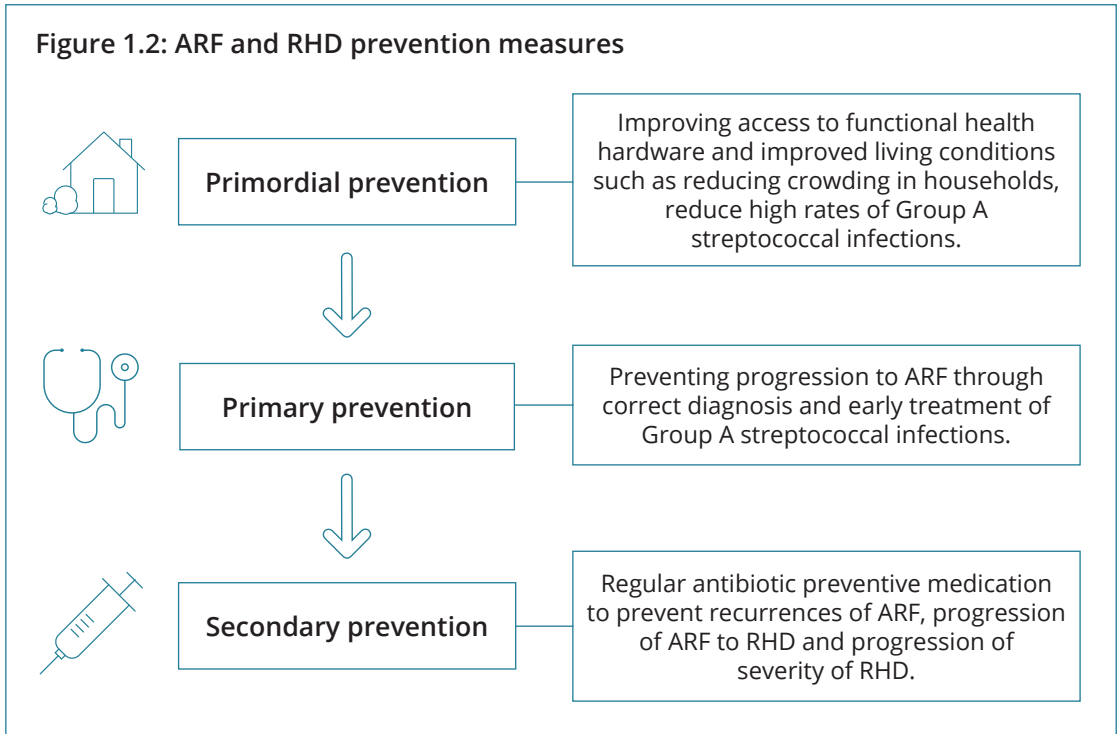
Figure 1.1: Diagram of the heart, emphasising the heart valves



ARF and RHD are preventable diseases

RHD is a disease of disadvantage. It is preventable and treatable. Both ARF and RHD are linked to overcrowding, socioeconomic deprivation, and low levels of functioning 'health hardware' (for example, working toilets, showers, taps) (Sims et al. 2016; Wyber & Carapetis 2015).

Prevention of ARF and RHD can occur at multiple stages, including prevention of initial GAS infection, prevention of initial ARF episode and prevention of subsequent GAS infections or ARF episodes (Figure 1.2).



RHD control programs and registers in states and territories

The Australian Government provides funding to support RHD control programs in Queensland, Western Australia, South Australia, and the Northern Territory.

These programs:

- identify people with, or at risk of, ARF and RHD
- promote primary prevention of ARF
- support the delivery of long-term secondary prevention treatment
- increase awareness of ARF and RHD among health professionals
- provide education about ARF and RHD to health professionals, patients and their families, and communities
- maintain disease registers for people diagnosed with ARF or RHD, to monitor health outcomes and improve control program activities

An RHD program and register also operates in New South Wales, but is not currently covered under the Australian Government's Rheumatic Fever Strategy. This report describes data from Queensland, Western Australia, South Australia, and the Northern Territory. Data from New South Wales are included in a separate section.

How many people have ARF and/or RHD?

As at 31 December 2017, almost 6,400 people were living with a diagnosis of ARF and/or RHD in Queensland, Western Australia, South Australia, and the Northern Territory. For both males and females, those aged 5–14 are the most likely to be on the registers (Figure 1.3).

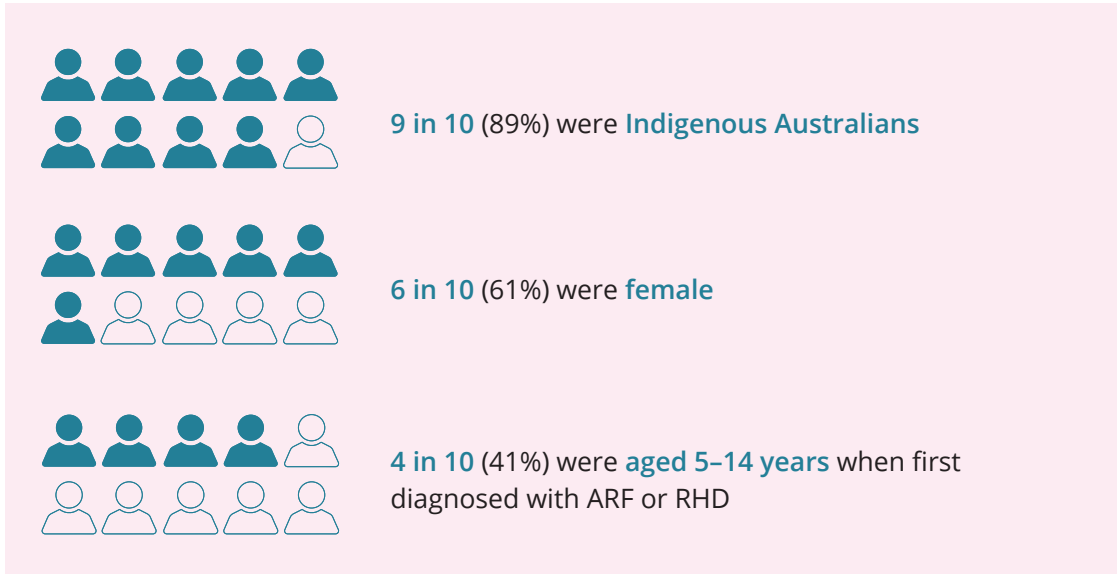
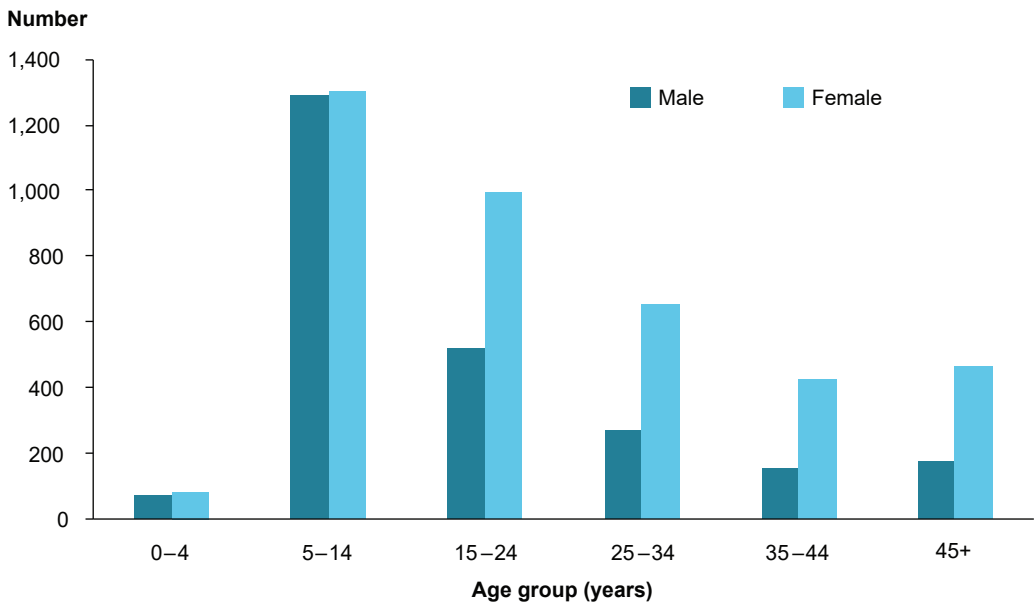


Figure 1.3: People on ARF/RHD registers, by age and sex, 31 December 2017

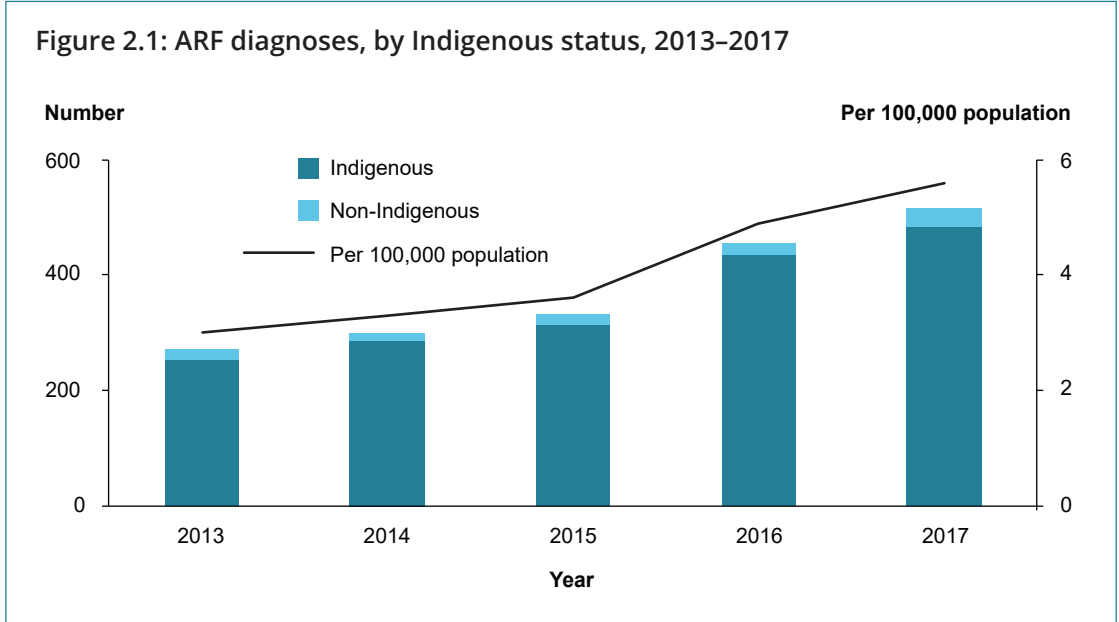


2 Acute rheumatic fever

This section discusses diagnoses of ARF reported by the RHD control programs. The total number of ARF patients recorded on registers depends on the varying reporting practices of each program. It is likely that the numbers presented in this section underestimate the true number of ARF episodes in the community.

ARF among all Australians

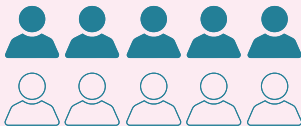
In 2013–2017, about 1,897 people were diagnosed with ARF, a rate of 4 per 100,000 population. The number and rate of diagnoses rose over the period, from 3 per 100,000 population in 2013 (276 diagnoses) to 6 per 100,000 population (528 diagnoses) in 2017 (Figure 2.1).



The Northern Territory had the highest rate of ARF diagnoses (80 per 100,000 population; 973 diagnoses), followed by Western Australia (3 per 100,000; 330 diagnoses), Queensland (2 per 100,000; 525 diagnoses), and South Australia (1 per 100,000 population; 69 diagnoses).



9 in 10 (94%; 1,776 diagnoses) were **Indigenous Australians**



5 in 10 (51%; 964 diagnoses) were **people aged 5–14 years**



6 in 10 (56%; 1,060 diagnoses) were **female**

ARF among Indigenous Australians

In 2013–2017, 1,776 Aboriginal and Torres Strait Islander people were diagnosed with ARF, a rate of 85 per 100,000 population.

The Northern Territory had the highest rate of ARF diagnoses (260 per 100,000 population; 954 diagnoses), followed by Western Australia (67 per 100,000 population; 322 diagnoses), Queensland (42 per 100,000 population; 435 diagnoses), and South Australia (32 per 100,000; 65 diagnoses).

Age and sex

The rate of ARF was **higher for Indigenous females** than males.



96 per 100,000 population
(1,006 diagnoses)

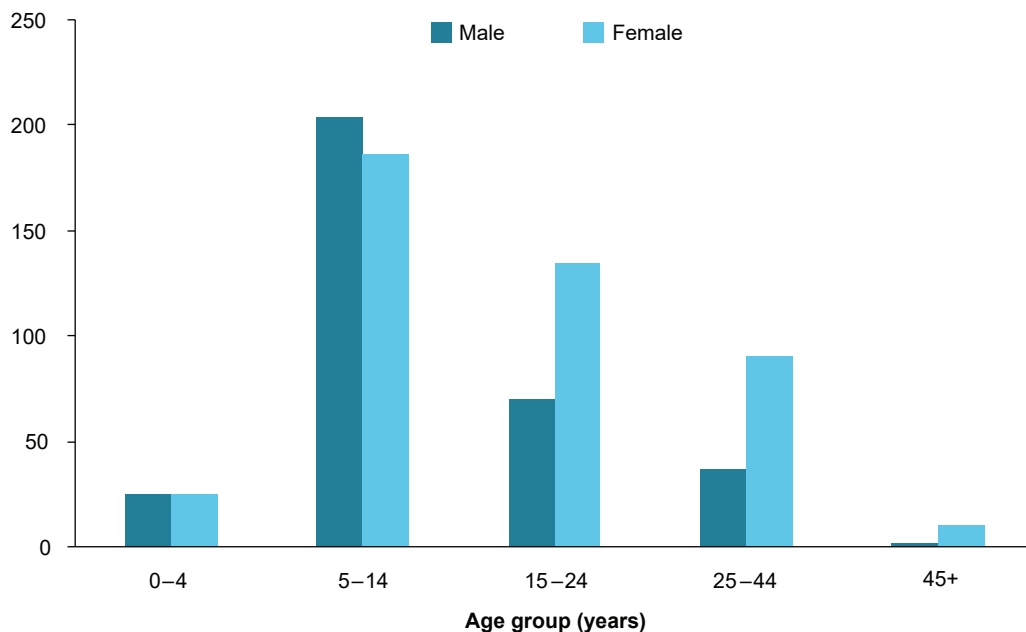


74 per 100,000 population
(770 diagnoses)

In 2013–2017, ARF diagnosis rates among Indigenous Australians were highest among young people aged 5–14 (Figure 2.2).

Figure 2.2: ARF diagnoses among Indigenous Australians, by age at diagnosis and sex, 2013–2017

Per 100,000 population



Location

For each ARF episode, the region where the person was when they first presented with symptoms, and the region where they most recently received their secondary prophylaxis were recorded. The location where they became infected with group A streptococcus (GAS) is not captured, and in many cases cannot be determined.

Indigenous Australians with ARF were most likely to first experience symptoms in Northern Australia (northern Queensland, northern Western Australia, and the Northern Territory). The ongoing management of cases was distributed more evenly between Northern Australia and remote parts of Queensland, Western Australia, and South Australia.



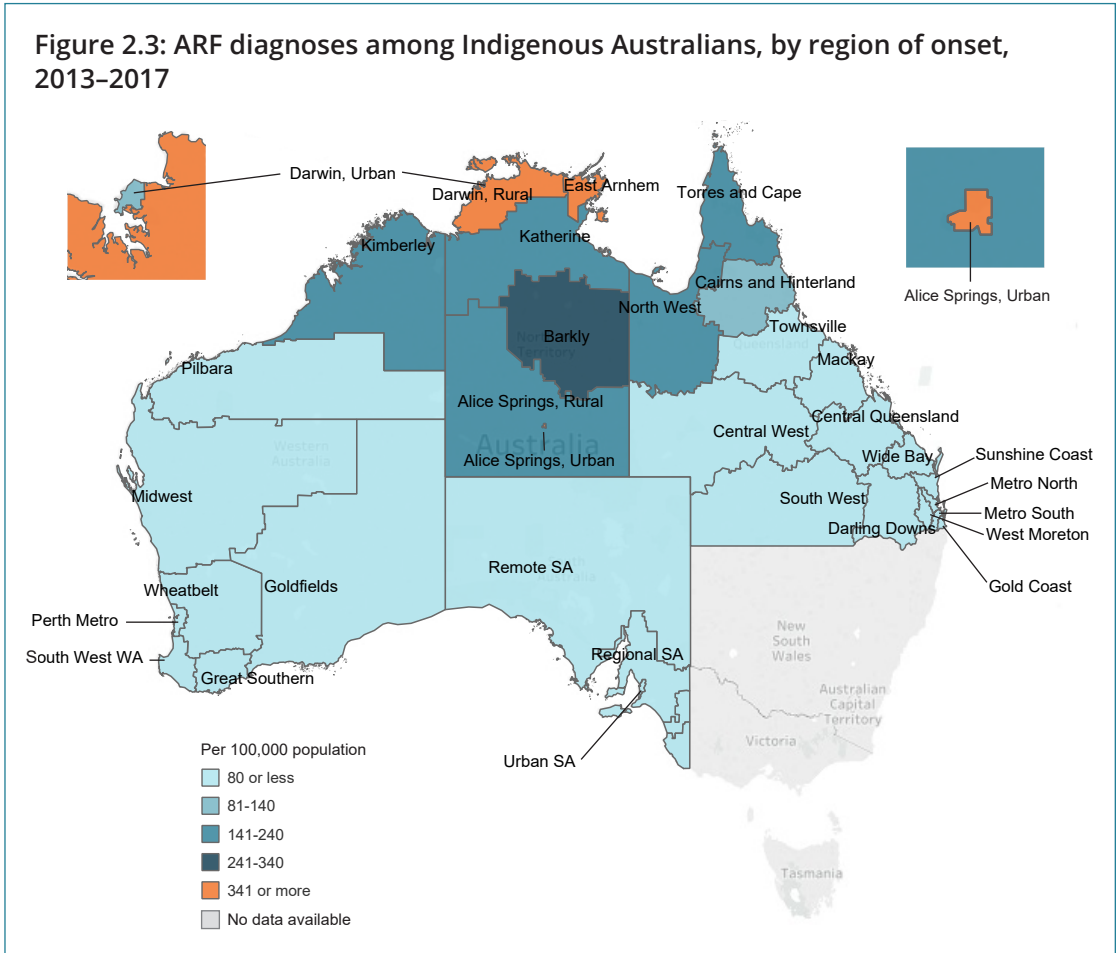
Did you know?

Each state or territory defines regions uniquely, based on its own specific health services boundaries. There are 33 regions spread over the Queensland, Western Australia, South Australia, and the Northern Territory. Regions do not cross state and territory boundaries.

Region of onset

The region of onset is the region of the health service where the person first presented with symptoms consistent with an ARF episode.

The region with the highest ARF onset rate among Indigenous Australians was rural Darwin (391 per 100,000 population; 252 diagnoses). Urban Alice Springs (371 per 100,000; 124 diagnoses) and East Arnhem in the Northern Territory (357 per 100,000; 207 diagnoses) also had high rates (Figure 2.3).

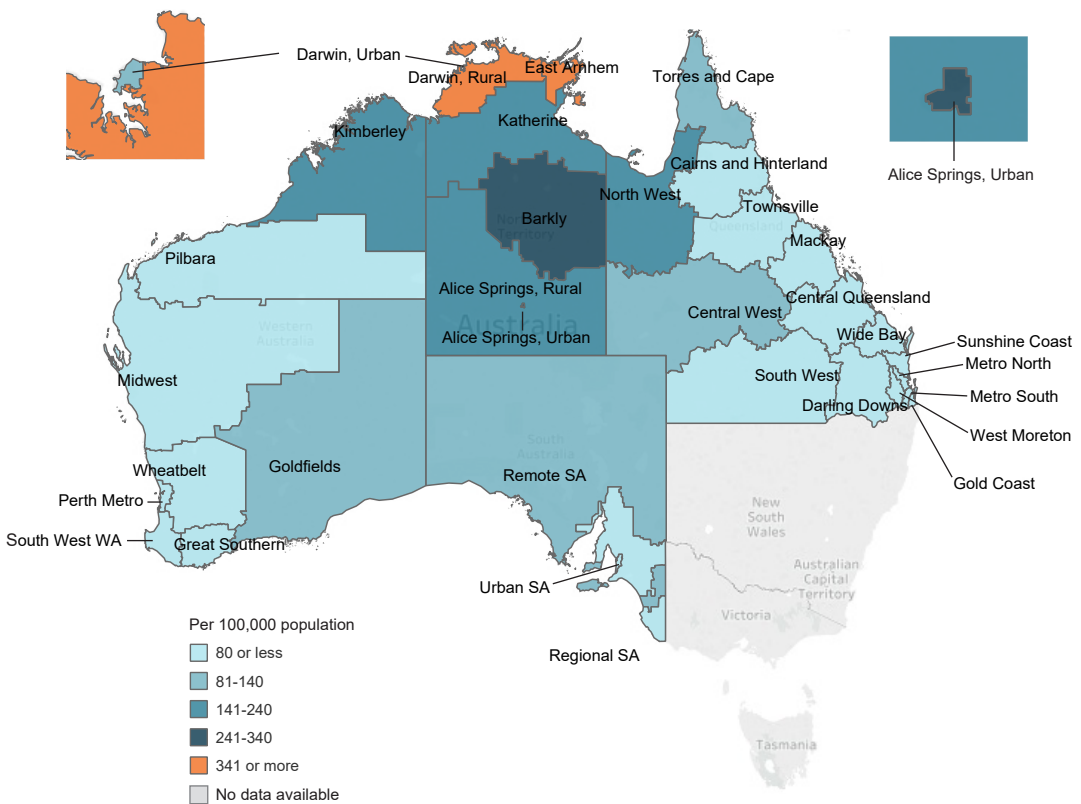


Region of management

Region of management is where the patient receives the majority of their primary health care, particularly their ongoing preventative antibiotics. The geographic region in which an ARF case is managed is regularly updated on registers.

In 2013–2017, rural Darwin in the Northern Territory managed the greatest number of Indigenous Australians with recently diagnosed ARF (387 per 100,000 population; 249 diagnoses). East Arnhem in the Northern Territory (366 per 100,000; 212 diagnoses) and the Kimberley in Western Australia (200 per 100,000; 180 diagnoses) also had high rates (Figure 2.4). Note that primary health care services also managed cases diagnosed before 2013, which are not included in these rates.

Figure 2.4: ARF diagnoses among Indigenous Australians, by region of management, 2013–2017



Note: Region of management is the region at the time of data extraction, which might have changed during the 2013–2017 period.

ARF recurrences

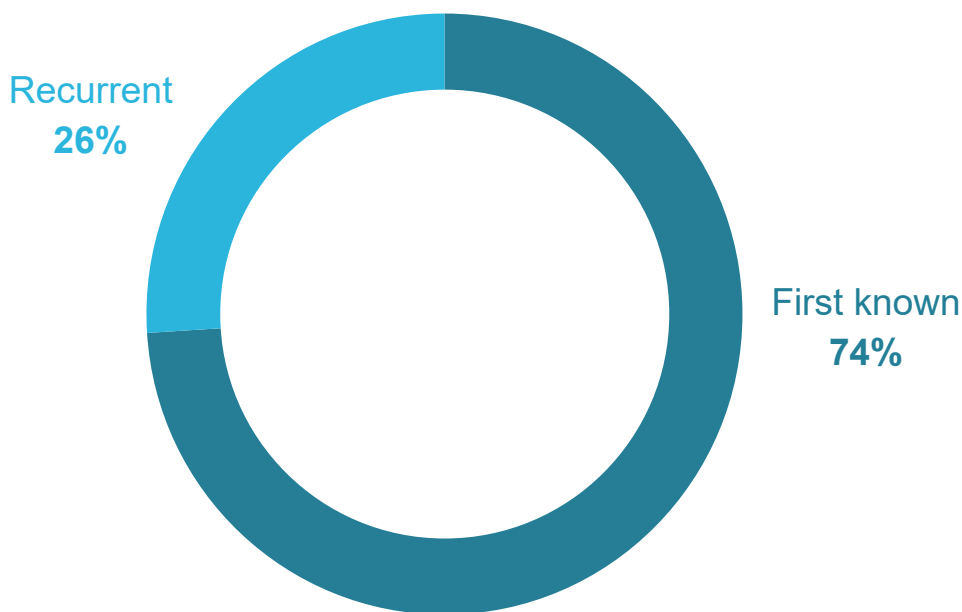
Box 2.2: ARF recurrence status definitions

First known episode: A reported ARF episode (definite, probable, or possible) in an individual with no known past ARF or RHD.

Recurrent episode: A reported ARF episode (definite, probable, or possible) in an individual with known past ARF or RHD.

ARF recurrences are preventable, through secondary prophylaxis. In 2013–2017, the majority were first known episodes (1,316 diagnoses) and about one-quarter of ARF diagnoses among Indigenous Australians were recurrences (460 diagnoses) (Figure 2.5).

Figure 2.5: ARF recurrences among Indigenous Australians, 2013–2017



The number and rate of recurrent ARF diagnoses rose from 14 per 100,000 population (57 diagnoses) in 2013 to 31 per 100,000 population (136 diagnoses) in 2017, but represented about one-quarter of diagnoses each year.

The proportion of ARF diagnoses that were recurrences increased with age, and was higher among females than males.

3 Rheumatic heart disease

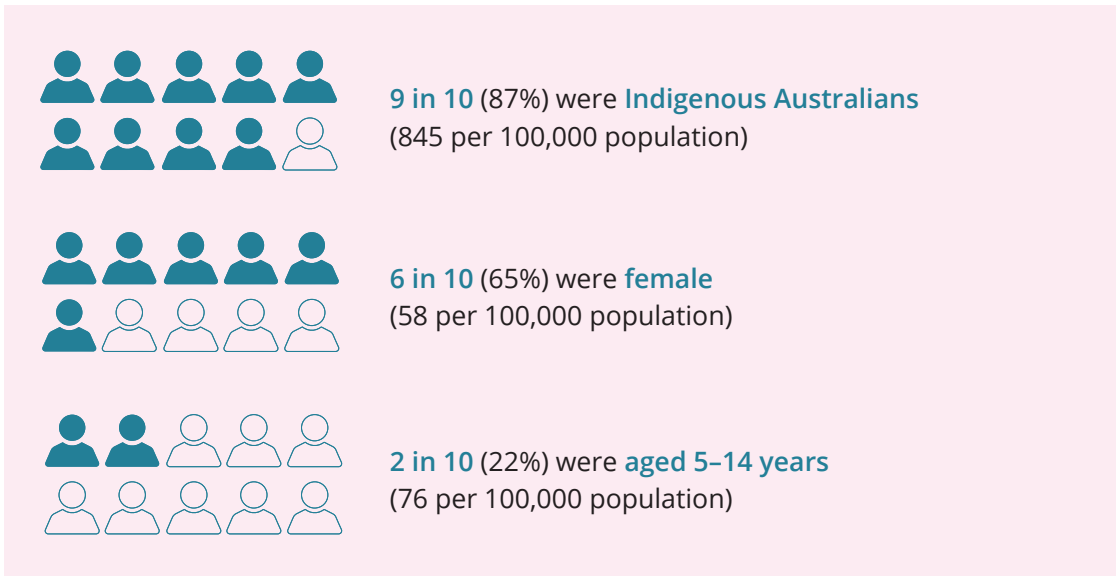


The National Rheumatic Heart Disease data collection includes information about diagnoses of RHD recorded in each jurisdiction. The year each register began varies—1997 in the Northern Territory, 2009 in Queensland and Western Australia, and 2012 in South Australia.

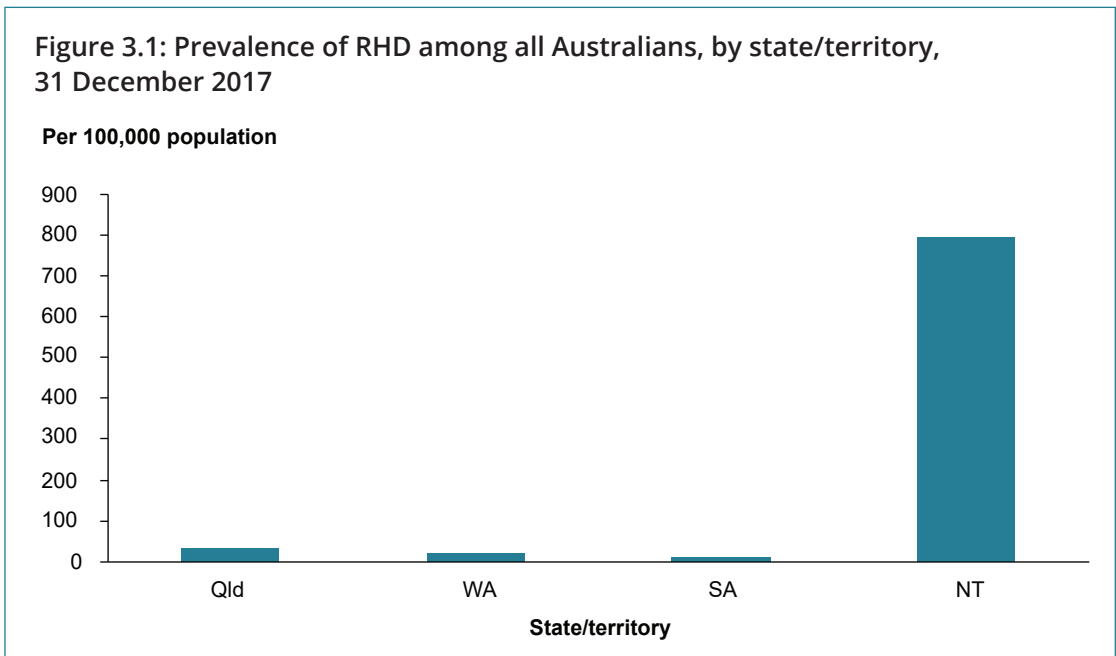
A person can only have 1 diagnosis of RHD, but might appear on more than 1 register, if they receive treatment in different places. For the national data collection, each diagnosis was assigned to only 1 jurisdiction.

RHD among all Australians

As at 31 December 2017, 4,255 people (45 per 100,000 population) were recorded as having RHD on registers in Queensland, Western Australia, South Australia, and the Northern Territory.



As at 31 December 2017, the Northern Territory (793 per 100,000 population; 1,951 patients) had the highest rate of recorded RHD patients, while South Australia (11 per 100,000; 181 cases) had the lowest (Figure 3.1).

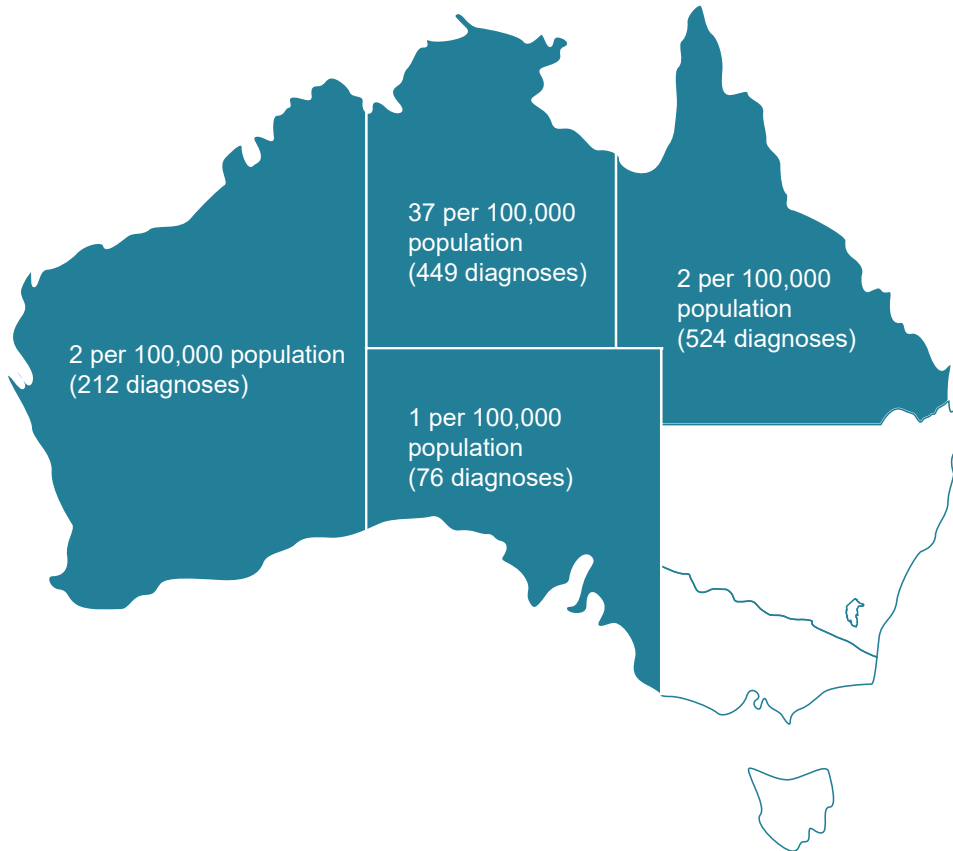


New RHD diagnoses among all Australians

In this report, a new RHD diagnosis is defined as a diagnosis that was made between 1 January 2013 and 31 December 2017. These will be the focus of the analysis in the next sections.

In 2013–2017, 1,261 Australians were diagnosed with RHD for the first time (3 per 100,000 population) (Figure 3.2).

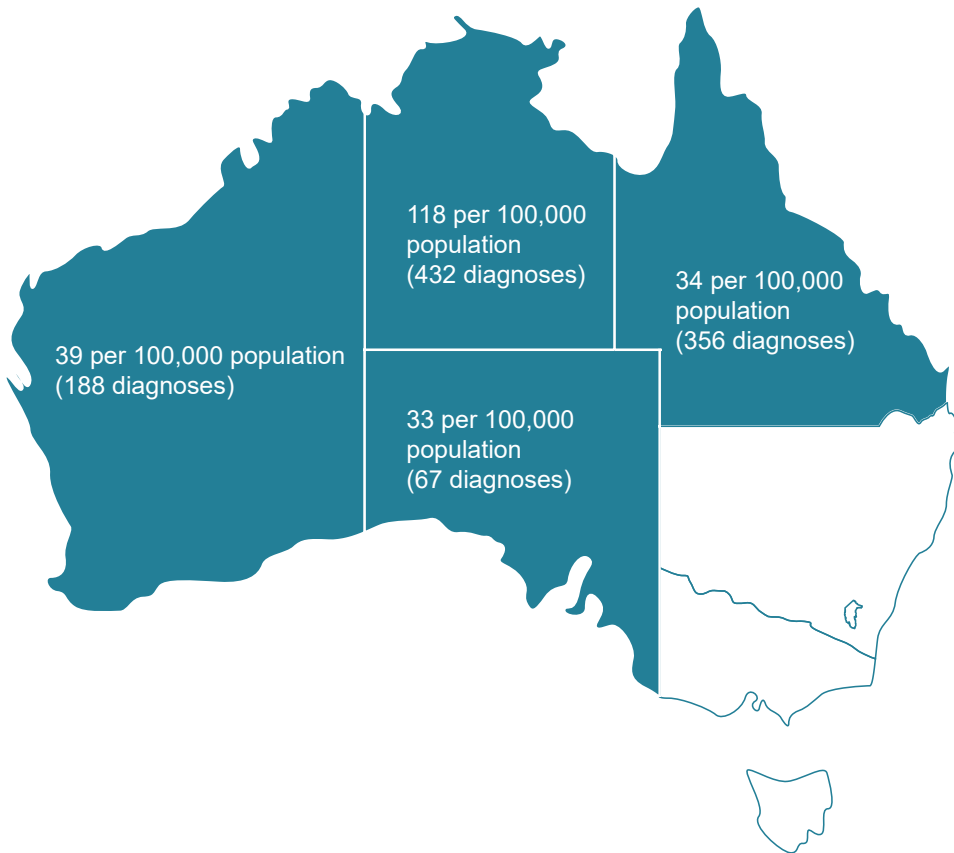
Figure 3.2: New RHD diagnoses among all Australians, by state/territory, 2013–2017



New RHD diagnoses among Indigenous Australians

In 2013–2017, 1,043 Indigenous Australians were diagnosed with RHD. The Northern Territory (118 per 100,000 population; 432 diagnoses) had the highest rate, followed by Western Australia (39 per 100,000; 188 diagnoses), Queensland (34 per 100,000; 356 diagnoses), and South Australia (33 per 100,000; 67 diagnoses) (Figure 3.3).

Figure 3.3: New RHD diagnoses among Indigenous Australians, by state/territory, 2013–2017



Age and sex

The rate of new RHD in Indigenous females was about twice the rate in Indigenous males.



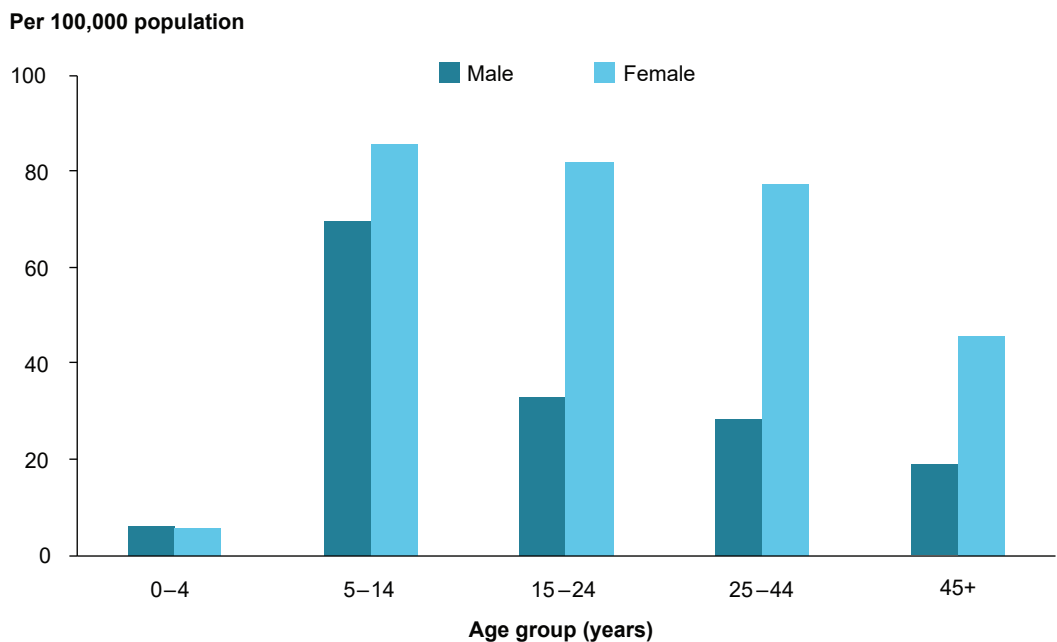
65 per 100,000 population
(685 diagnoses)



34 per 100,000 population
(358 diagnoses)

Nearly 60% of new RHD diagnoses were among people aged under 25 when diagnosed (Figure 3.4).

Figure 3.4: New RHD diagnoses among Indigenous Australians, by age and sex, 2013–2017

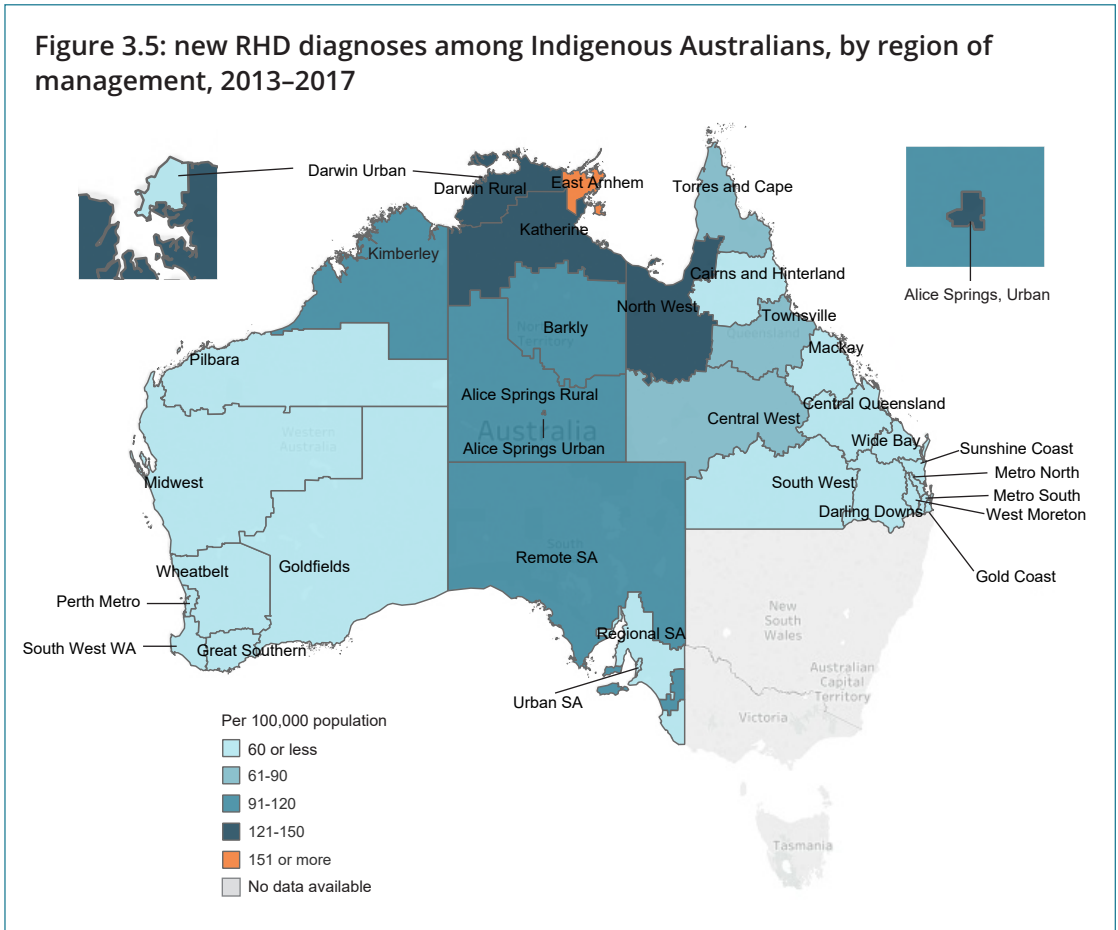


Region of management

The region of management is where the patient receives the majority of their primary health care for RHD.

Among Indigenous RHD cases diagnosed in 2013–2017, East Arnhem in the Northern Territory had the highest rate (179 per 100,000 population; 104 diagnoses), followed by north-west in Queensland (145 per 100,000; 64 diagnoses) (Figure 3.5).

Figure 3.5: new RHD diagnoses among Indigenous Australians, by region of management, 2013–2017



Characteristics at time of RHD diagnosis among Indigenous Australians

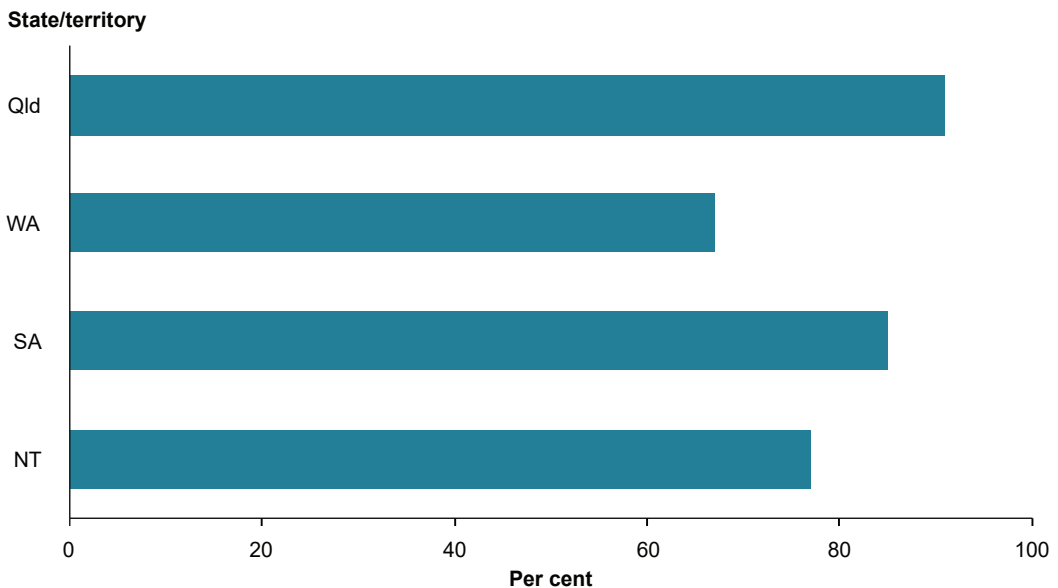
RHD patients who have no documented previous ARF episode

Among all Indigenous Australians with a new RHD diagnosis in 2013–2017, about 4 in 5 (838 diagnoses) did not have a previous ARF episode recorded on the registers. The proportion was similar between males and females, but varied between state and territory (Figure 3.6).

Did you know?

RHD only occurs in someone who has had ARF, but some people with RHD have no recorded previous ARF episode on state and territory registers. There are various reasons why ARF might not be notified to a register, such as being diagnosed before the relevant register began.

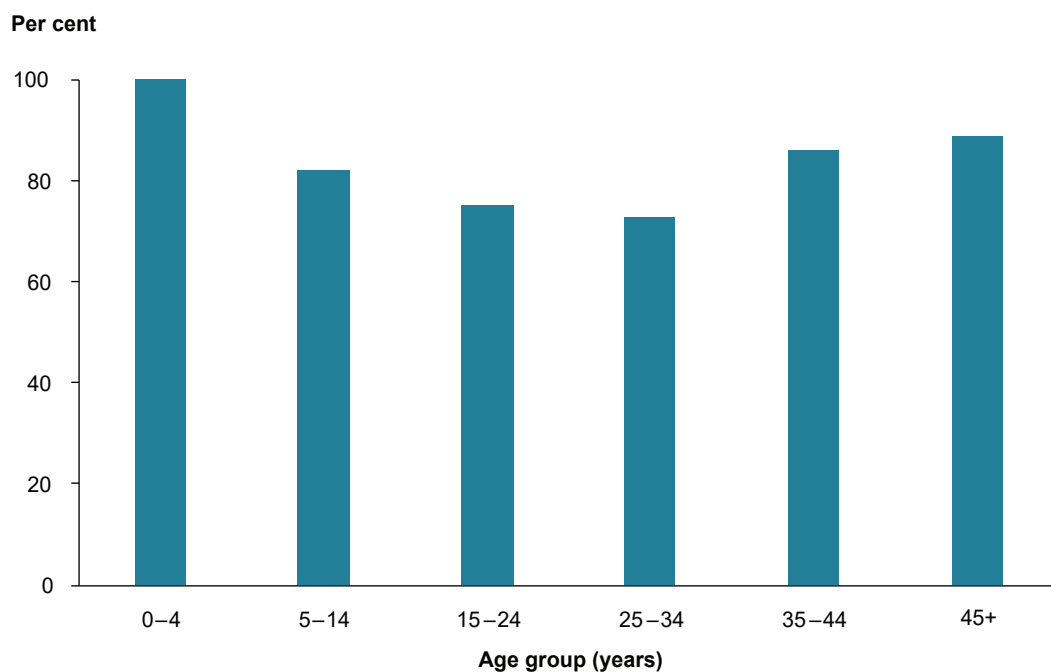
Figure 3.6: New RHD diagnoses among Indigenous Australians with no previous ARF recorded, by state/territory, 2013–2017



Note: in Queensland, the proportion of RHD diagnoses with no previous ARF recorded is overestimated due to the timing of notification legislation.

Among Indigenous Australians, children aged 0–14, and those aged 35 and over were more likely than those aged 15–34 to have had no previous ARF recorded at the time of RHD diagnosis (Figure 3.7).

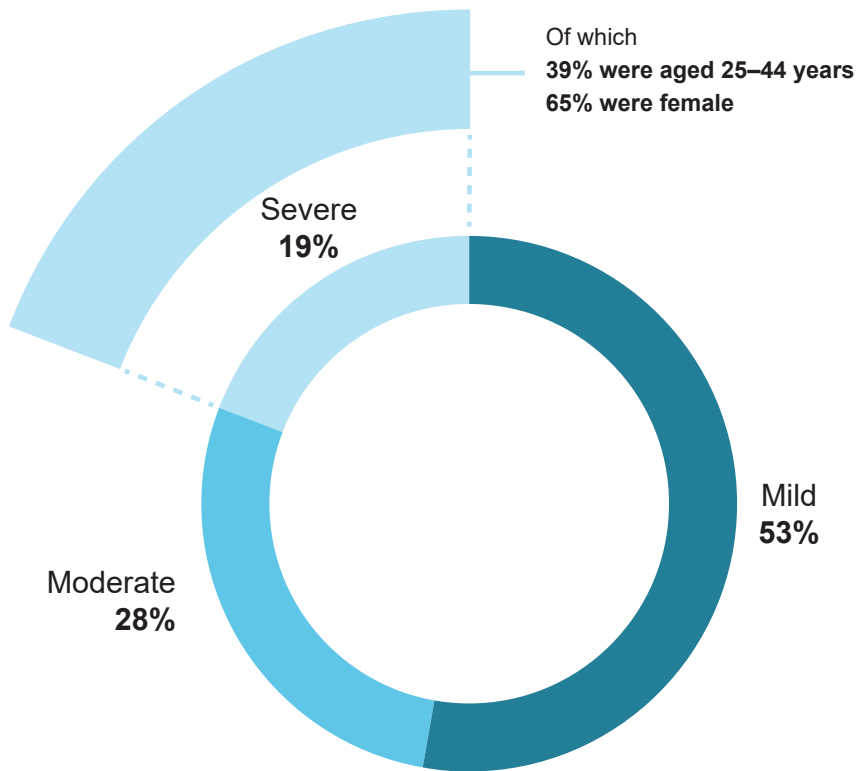
Figure 3.7: New RHD diagnoses among Indigenous Australians with no previous ARF recorded, by age, 2013–2017



Severity of RHD at time of diagnosis

Of the 1,043 Indigenous Australians who were diagnosed with RHD in 2013–2017, more than half had mild RHD at diagnosis (53%; 552 diagnoses), more than one-quarter (28%; 288 diagnoses) had a moderate status at diagnosis, and 19% (196 diagnoses) had severe RHD at diagnosis (Figure 3.8).

Figure 3.8: RHD among Indigenous Australians, by severity at time of diagnosis, 2013–2017



Box 3.2: Definitions of severity status (priority level)

Severe (Priority 1): Severe damage to the heart valves, or moderate to severe heart valve damage with symptoms of heart failure.

Moderate (Priority 2): Any moderate heart valve damage without symptoms, and with normal left ventricle function.

Mild (Priority 3): Mild heart valve disease.

Inactive (Priority 4): Patients with a history of ARF (no RHD) for whom secondary prophylaxis has been ceased.

Source: RHD Australia 2012.

Surgery among Indigenous Australians with RHD

RHD leads to damage to the heart valves—the mitral, aortic, pulmonary, and tricuspid valves. The damaged heart valves might need surgery to replace or repair the valve.

In 2013–2017, 460 people diagnosed with RHD had surgery. Of those, almost three-quarters (70%; 322 people) were Indigenous Australians with RHD. These 322 people underwent 350 surgical events—the majority had 1 surgery, while 23 had up to 4 surgical events.

About half of the surgeries were for people from the Northern Territory (176 surgical events), and one-third (112) were from Queensland.



8 in 10 (77%) under 45 years
(270 events)



67% female
(234 events)



42 surgeries in children aged 5–14 years

During the 350 surgical events, 477 individual surgical procedures were performed.



62% were on the mitral valve



62% were valve replacements
(mechanical or bioprosthetic)

All-cause deaths among all Australians with RHD

In 2013–2017, 275 deaths were reported to registers among individuals diagnosed with RHD. Of these, 221 (80%) were Indigenous Australians. The Northern Territory (40 per 100,000 population; 148 deaths) had the highest rate of deaths among Indigenous Australians with an RHD diagnosis (Figure 3.9). The cause of death is not captured in the registers, so is not necessarily related to RHD.

Figure 3.9: All-cause deaths among Indigenous Australians with an RHD diagnosis, by state/territory, 2013–2017

Per 100,000 population



4 Secondary prophylaxis among Indigenous Australians

Secondary prophylaxis refers to the antibiotics given to people who have had a diagnosed ARF episode to prevent further GAS infections, and thereby reducing the risks of developing ARF again and of developing or worsening RHD. Secondary prophylaxis with regular benzathine penicillin G (BPG) is the only RHD control strategy shown to be clinically effective and cost effective at community and individual levels (RHD Australia et al. 2012).

The recommended regimen to prevent recurrences of ARF and progression of RHD involves regular intramuscular injections of BPG every 21–28 days. The duration of treatment depends on the age of the affected person and other factors, but is likely to be 10 years or more.

Secondary prophylaxis among Indigenous Australians

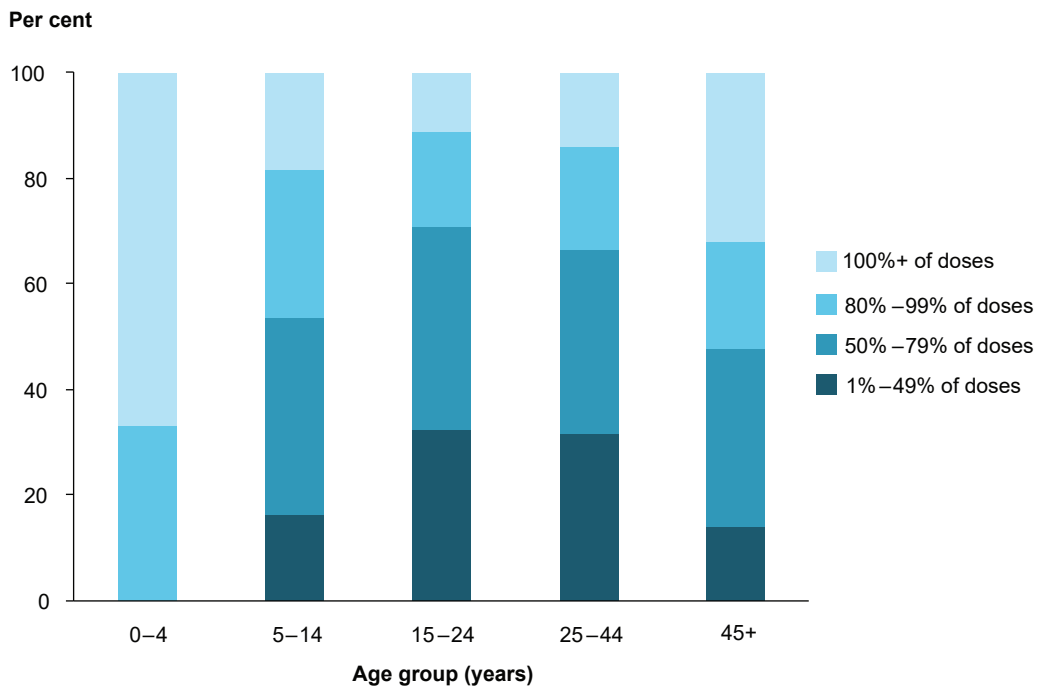
In 2017, 2,630 Indigenous Australians were prescribed a 28-day regime of BPG prophylaxis for the entire year, and received at least 1 dose.



- 15% (394 people) received 100% or more of their prescribed doses
- 21% (548 people) received 80%–99% of their prescribed doses
- 37% (964 people) received 50%–79% of their prescribed doses
- 27% (724 people) received less than 50% of their prescribed doses

Indigenous adolescents and young adults (aged 15–24) had generally lower adherence than other age groups, with one-third (33%) of people of this age receiving less than half of their prescribed doses. Almost half (46%) of those aged 5–14, and more than half (52%) of those aged 45 and over received at least 80% of their prescribed doses (Figure 4.1).

Figure 4.1: Adherence level among Indigenous Australians prescribed a 28-day BPG regime, by age, 2017



Note: This analysis only includes people who were prescribed prophylaxis for the whole of 2017.

A closer look—New South Wales



The New South Wales RHD register provides data directly to the AIHW. This register is funded by NSW Health.

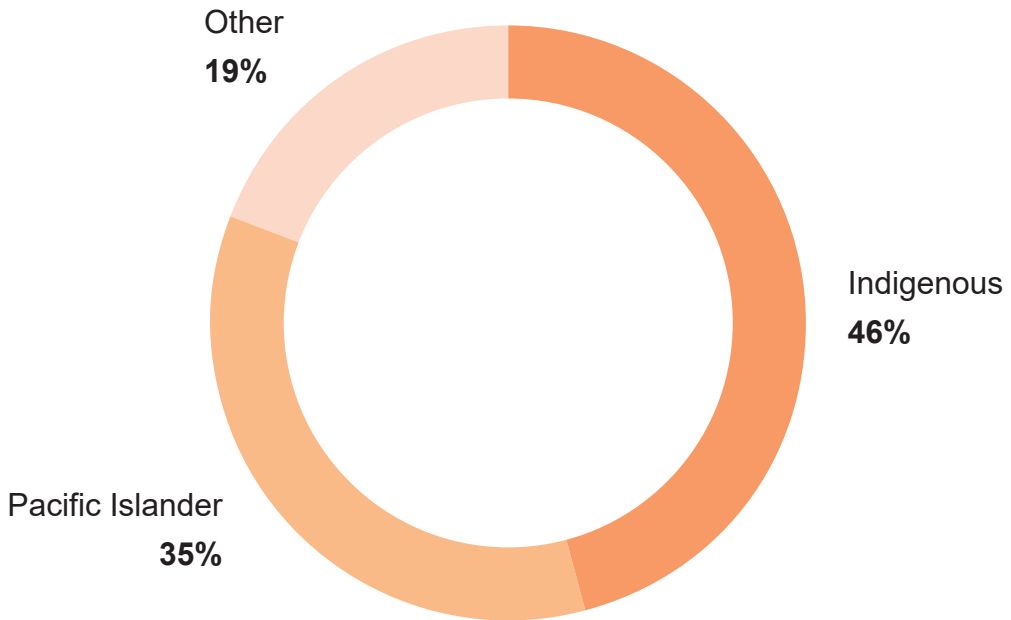
ARF, and RHD in people aged less than 35, became notifiable in New South Wales in October 2015, and the register was established in May 2016. It captures patients with ARF and RHD who consented to their information being on the register.

Data reported in this section are from October 2015 to 31 December 2017.

Acute rheumatic fever

Between October 2015 and December 2017, 43 people were diagnosed with ARF in New South Wales. About 46% (20 diagnoses; 4 per 100,000 population) were in Indigenous Australians (includes 1 person who identified as both Indigenous and from another high-risk group) (Figure 5.1).

Figure 5.1: ARF diagnoses in New South Wales, by high-risk population, October 2015–December 2017



For Indigenous Australians, ARF diagnosis was most common among:



those aged 5–14 years
(11 per 100,000 population;
12 diagnoses)

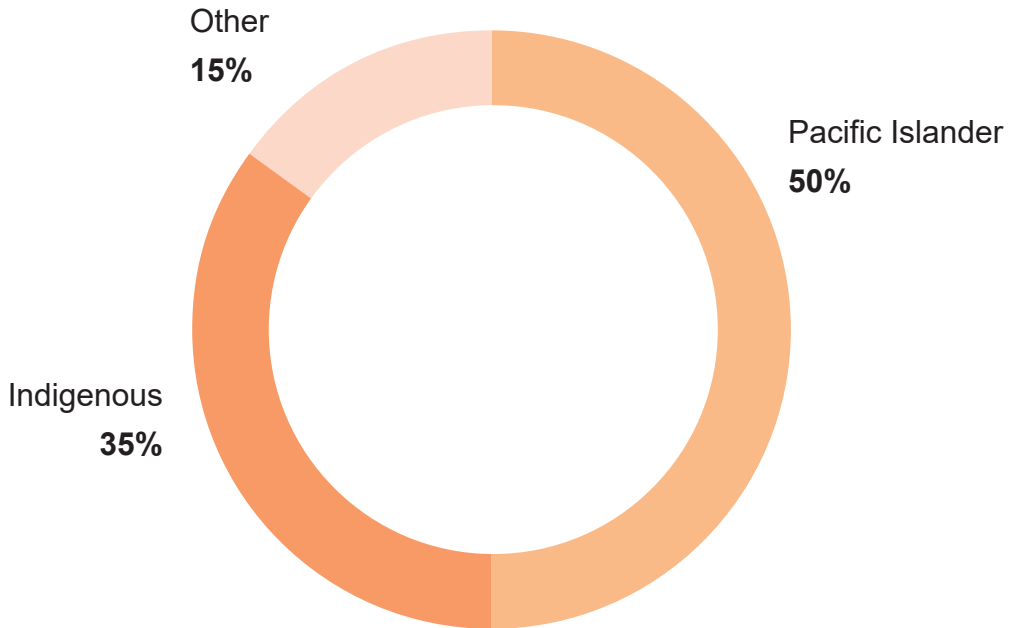


females (5 per 100,000
population; 12 diagnoses)

Rheumatic heart disease

Between October 2015 and December 2017, 44 people were diagnosed with RHD in New South Wales. Nearly half the diagnoses (20 diagnoses) were in people who identified as Pacific Islander (Figure 5.2).

Figure 5.2: RHD diagnoses in New South Wales, by high-risk population, October 2015–December 2017



For Indigenous Australians, RHD diagnosis was most common among:



those aged 5–14 years
(7 per 100,000 population;
8 diagnoses)

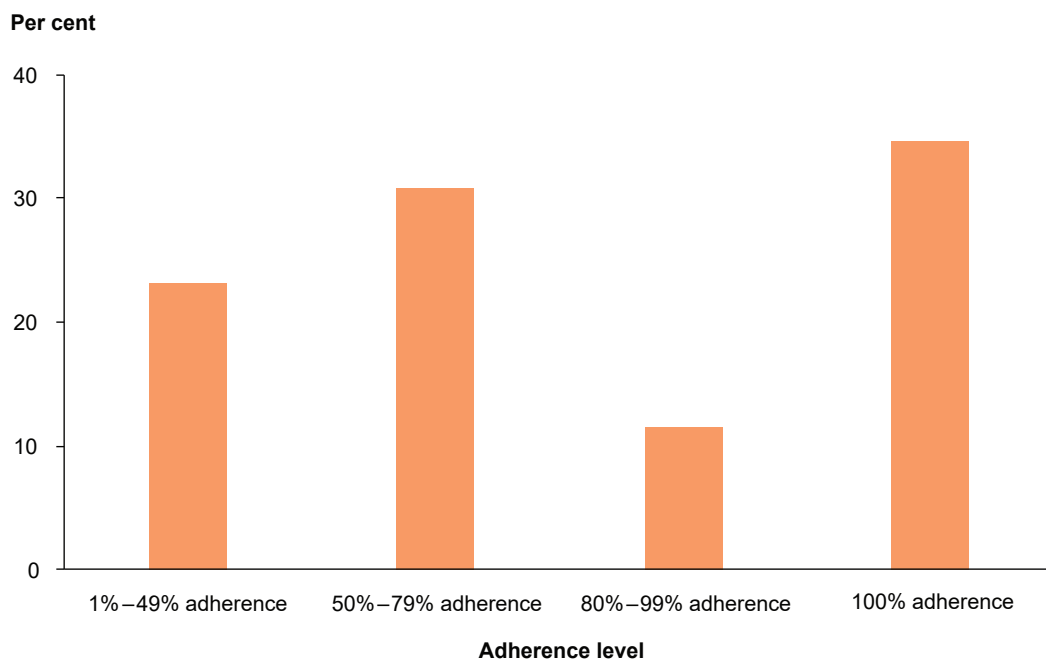


females (4 per 100,000
population; 10 diagnoses)

Secondary prophylaxis

Among all patients with ARF and/or RHD on a 21-day or 28-day BPG regime during 2017, about one-third (35%; 9 patients) received all of their prescribed doses (Figure 5.3).

Figure 5.3: Adherence level among New South Wales patients prescribed a 21-day or 28-day BPG regime, 2017

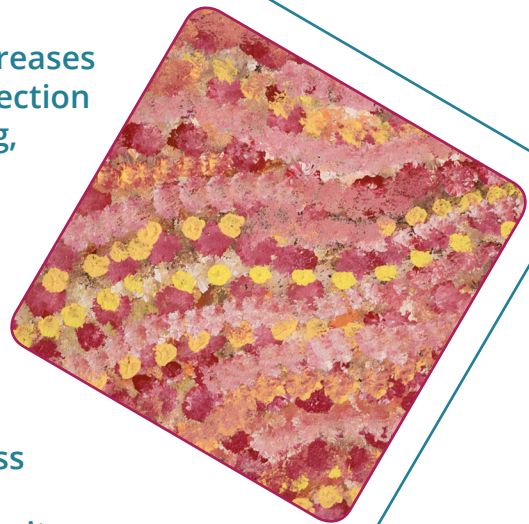


5 Socioeconomic factors

Socioeconomic deprivation and non-functioning health hardware increases the likelihood of ARF and RHD. This section looks at factors such as overcrowding, housing standards, and health service accessibility for Indigenous Australians.

This section draws on data from various sources to provide information about key risk factors associated with ARF and RHD, and to show how these are distributed across Queensland, Western Australia, South Australia, and the Northern Territory.

The 2016 Census is referenced in the household overcrowding section, and the 2014–15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) was used to describe acceptable standards of living. Data from the Aboriginal Medical Service, Royal Flying Doctors Service, the General Practitioner Network, and Primary Health Network were used in the 'Location of services' section.



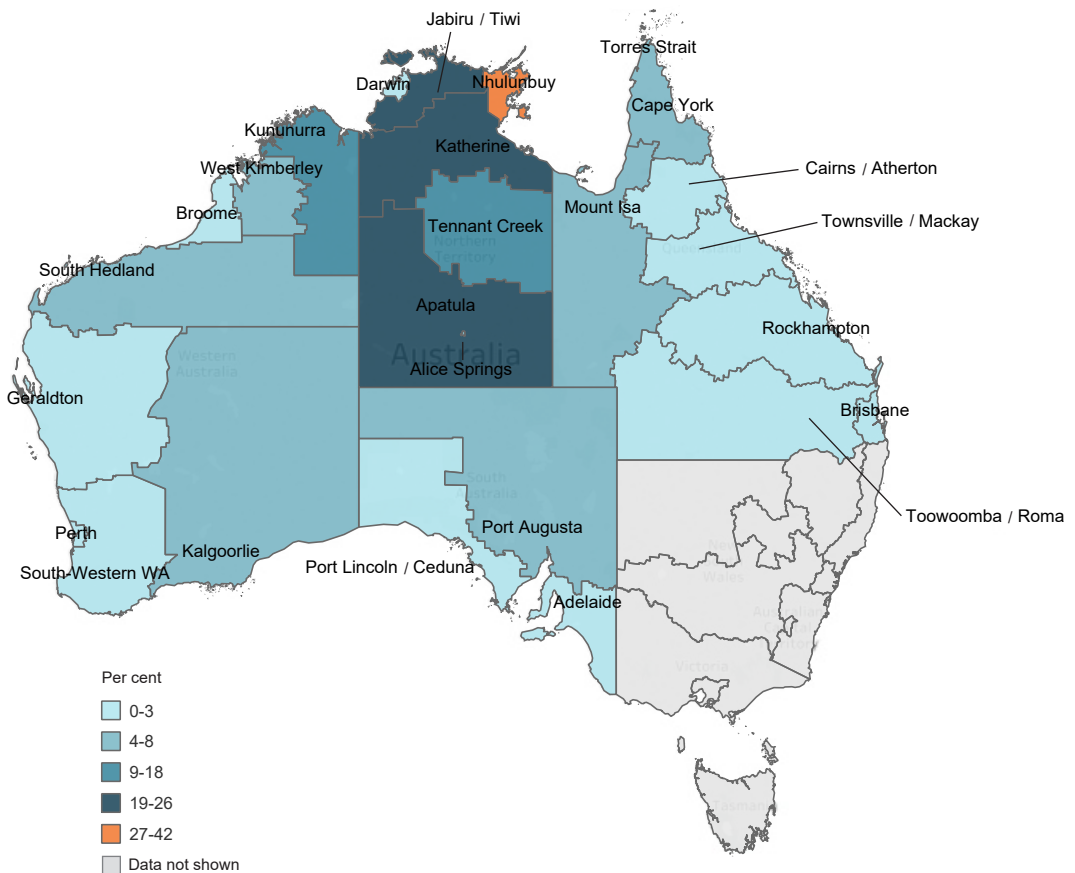
Household overcrowding

Household overcrowding is a known contributor to increased risk of group A streptococcus infection.

In 2016, the highest proportion of overcrowding among Indigenous Australians was in the Nhulunbuy region, East Arnhem Land in the Northern Territory, with 42% (3,845) of surveyed households being classified as severely overcrowded (Figure 6.1).

About 71% of all ARF cases are managed in regions that also have the highest rates of household overcrowding (all Northern Territory regions, the Kimberley in Western Australia, and Torres Strait and Cape York in Queensland).

Figure 6.1: Indigenous Australians living in severely crowded dwellings, by region, 2016



Note: Severe household crowding means living in a dwelling that requires 4 or more extra bedrooms to accommodate the people who usually live there, as defined by the Canadian National Occupancy Standard.

Source: AIHW analysis of Census 2016 using TableBuilder©.

Dwelling standards

Acceptable dwellings are important in reducing the risk of group A streptococcus transmission and infection.

A house is deemed to not be of an acceptable standard (according to the Australian Bureau of Statistics) if it has more than 2 structural problems or has no:

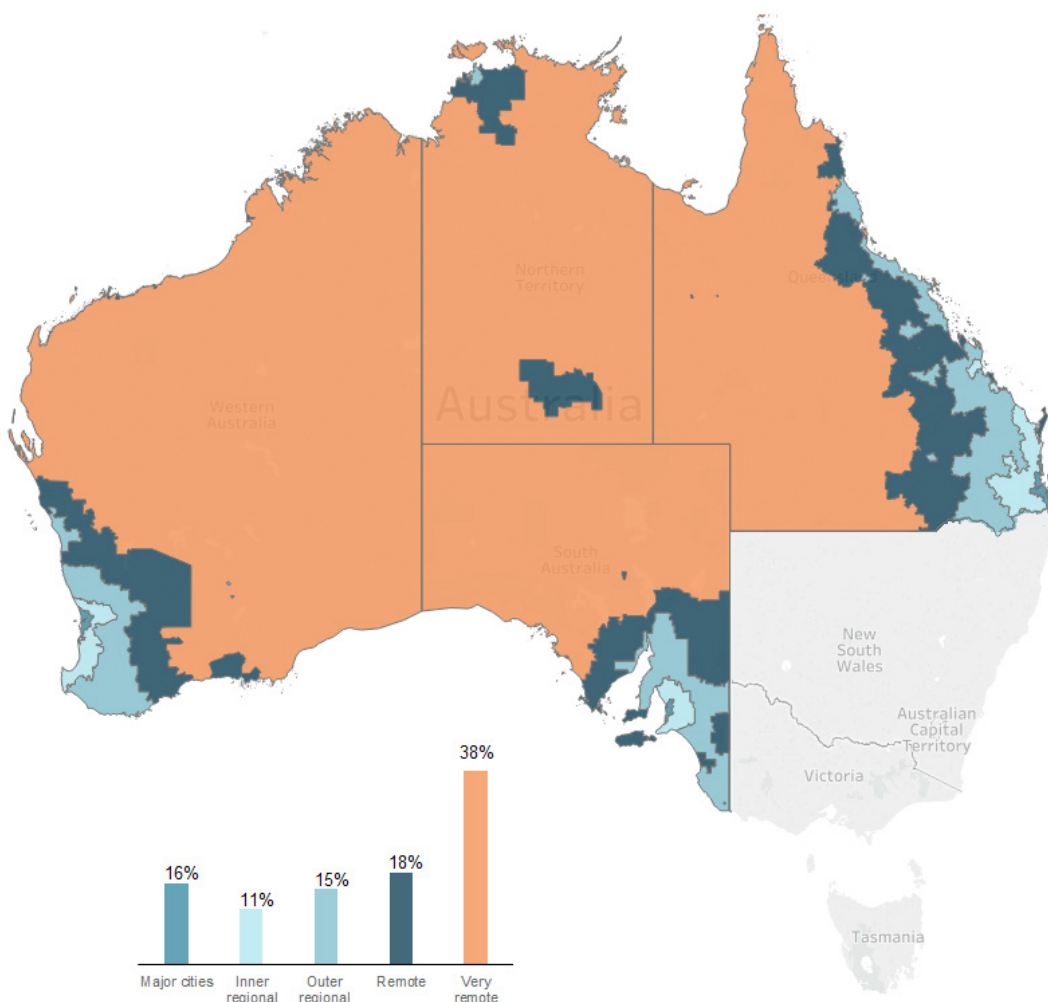
- working facilities for washing people
- working facilities for washing clothes or bedding
- working facilities for preparing food
- working sewerage facilities.

In 2014–2015, *Very remote* areas of Queensland, Western Australia, South Australia, and the Northern Territory had the highest rate of Indigenous Australians living in dwellings that were not of an acceptable standard (38%; 33,600 people).

In *Remote* areas, 18% of the Indigenous population lived in a house of an unacceptable standard (8,200 people), compared with 15% in *Outer regional* areas (14,400 people), 11% in *Inner regional* areas (5,600 people), and 16% in *Major cities* (17,800 people) (Figure 6.2).

Data on acceptable dwelling standards are not available at a regional level.

Figure 6.2: Indigenous Australians living in a house of unacceptable standard, by remoteness area, 2014–15



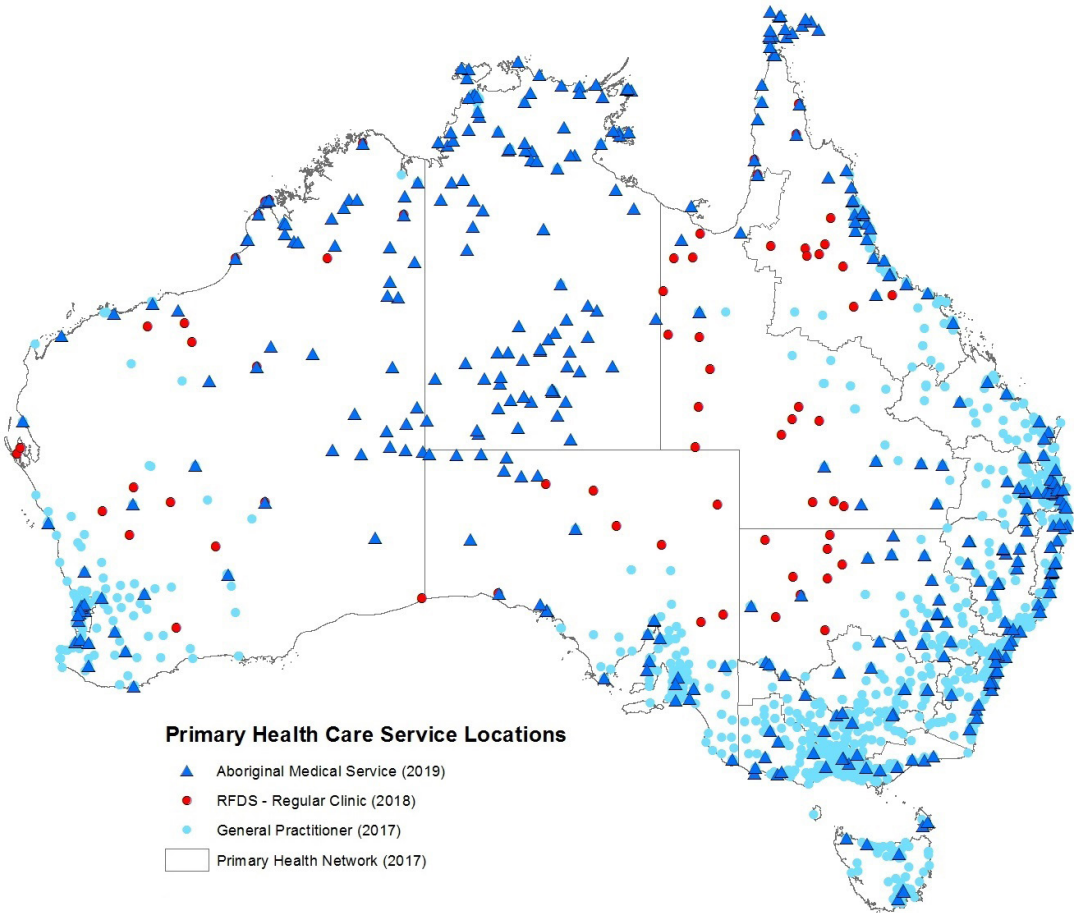
Source: AIHW analysis of 2014–15 National Aboriginal and Torres Strait Islander Social Survey using TableBuilder®.

Location of services

Access to services is essential to diagnose and treat ARF, and prevent RHD. Indigenous-specific services are crucial in treating and preventing ARF and RHD.

There were 97 Indigenous medical services in the Northern Territory, 27 in country South Australia, 102 in Queensland, and 62 in country Western Australia (Figure 6.3).

Figure 6.3: Primary health-care service locations in Australia, 2017, 2018, or 2019



Note: Appearance on the map does not necessarily indicate that a site is a regular full-time practice.

Sources: RFDS 2018; DoH 2017; AMPCo 2017 and AIHW 2019.

Access to services

Drive times are an important indicator of access to services. Long drive times might have a negative impact on the management of ARF and RHD in the primary health-care sector.

Many Indigenous Australians living in remote areas do not live within 1 hour's drive of their nearest Indigenous-specific primary health-care service. While almost all Indigenous Australians in *Major cities* live close to their nearest service, only 47% of Indigenous Australians in *Very remote* areas do (AIHW 2015).

Pushing through: the challenge of rheumatic fever

By Corey Rivers, participant in Champions4Change program


“I was 9 years old when I first got sick. I had strange movements in my hands that made me drop things. This was scary for me. The sickness also made it hard for me to speak properly; I mumbled and felt really tired.

My mum took me to the hospital to get checked. I ended up having to stay there a long time—so long that I missed Christmas and the start of the school year. One reason for this was that it took the hospital people a long time to find out what was wrong with me.

My mum thought I had rheumatic fever. She had rheumatic fever when she was young and knew the symptoms. At first, the doctors did not listen to her. She was worried about me, and we were frustrated that no one seemed to be listening. But after lots of tests, and taking out my appendix, they agreed that I had rheumatic fever.

Now I need a needle every month to stop it coming back, and to keep my heart strong.

Having rheumatic fever caused me to miss a lot of school, and stopped me from being able to go to boarding school down south with my cousin. I was doing well at school before I had rheumatic fever, and I had really neat handwriting. Now the strange movements give me bad handwriting, and sometimes people think I am dumb. I know I am not dumb, but it is hard when people think you are.



I don't let these challenges get me down. In fact, I like setting myself challenges, like learning to play the trumpet—just to prove that I can do it. The thing I am most proud of is going well in sport. Being sick just made me try harder. At first I thought I couldn't play because of the sickness, but I pushed through, and now I don't let this get me down. I tell kids, "Don't let anyone put you down. Just say: I can play sports just like you. Probably better than you!"

Getting rheumatic fever is something I have had to step up to. I try to set a good example to my classmates and younger brothers and cousins. And I have even been given leadership awards at school. I have been asking for more help with my school work, and am now going well in exams.

I want to help other kids with rheumatic fever to do well too. I listen to them and try to help them out. I would like to support other kids who are getting the needle every month. I would tell them, "Just don't worry, it is going to help you get better". I would tell them how I was a bit frightened at first, and I went to the clinic kicking and screaming. But I would tell them that getting the needle is like letting your body heal. You don't want to miss needles, because then you will get sick again. But, look at me now. As I get older, I would like to go to the clinic by myself to get my needles. Not be dependent on my mum.

Sometimes I still want to just run away from it all, but if that happens, don't let it go too far. Ask for help. And don't let anyone put you down. You can push through."

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Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are preventable diseases disproportionately affecting Aboriginal and/or Torres Strait Islander Australians living in remote areas. Prevalence rates were highest in the Northern Territory, females, and young people aged 5–14. These data highlight the important role of jurisdictional control programs and registers in Queensland, Western Australia, South Australia, the Northern Territory and New South Wales.

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